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Collection of Gender Identity Data Using Electronic Medical Records: Survey of Current End-user Practices

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A transgender person may have a preferred name, preferred pronoun, and gender identity, any of which can differ from what is listed in their legal documentation. In addition to negatively impacting patient experiences (e.g., being called by a birth name rather than one's gender-congruent preferred name in a crowded waiting room), incomplete or inconsistent documentation of this information in an electronic medical record (EMR) can impact care (Kosenko, Rintamaki, Raney, & Maness, 2013; Melendez & Pinto, 2009). For example, a patient listed as male in the EMR may have a cervix and require related screening reminders and documentation of a physical examination (Deutsch et al., 2013; Melendez & Pinto, 2009; Mizock & Lewis, 2008; National Gay and Lesbian Task Force, 2011). Some EMR systems, as well as provider uses of such systems, fail outright to identify transgender patients; the resulting systematic erasure leads to reduced funding allocations as well as impaired quality improvement and research efforts (Bauer et al., 2009).

Collecting gender identity data has received support from a multitude of entities and reports including the Institute of Medicine (National Research Council, 2013), Healthy People 2020 (U.S. Department of Health and Human Services, 2010), the Affordable Care Act (Center for American Progress, 2012), the Institute of Medicine (2011), and the Joint Commission (2011). *Meaningful Use* refers to incentive programs implemented by the Centers for Medicare and Medicaid Services. These programs provide financial incentives for the meaningful use of certified electronic health record technology to improve patient care. The programs are staged in three steps with increasing requirements for participation (Centers for Medicare and Medicaid Services, n.d.). Gender identity was not included in Meaningful Use Stage 2 as the Office of the National Coordinator for Health Information Technology felt there was insufficient evidence to support a best practice for doing so; Stage 3 is currently under review (Cahill & Makadon, 2014; Carroll, 2012). While inclusion in Meaningful Use guidelines will be an essential step toward more universal adaptation of this process, recommendations based on rigorous and validating research to guide such an inclusion are lacking.

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That said, given the limited funding opportunities for such research as well as a paucity of active researchers in the field, it is conceivable that such studies (and researchers to conduct them) may take years to materialize. In the interim, it would seem unfortunate to, as one recent paper on the subject opined, "let the perfect be the enemy of the good" (Cahill & Makadon, 2014, p. 39) and miss an opportunity to integrate these parameters into Meaningful Use as well as the burgeoning field of EMR products.

Several recent publications have begun to explore the collection of gender identity and related information (i.e., preferred name and pronoun) from transgender patients, as well as how this information is documented using EMRs. Initial best practice recommendations from the World Professional Association for Transgender Health (WPATH) were recently published; however, little is known about current clinician end-user implementation and use patterns (Cahill & Makadon, 2014; Deutsch et al., 2013). Anecdotal experience suggests that data are collected in an inconsistent fashion and stored in inconsistent locations in the record across platforms and institutions, adding further mystery and confusion to what is already a challenging topic for some providers and clinic staff to understand.

Many experts have begun to recommend the use of a two-step process for the collection of gender identity information (Cahill & Makadon, 2014; Deutsch et al., 2013). This method involves first querying gender identity and then birth sex. Transgender persons can be identified as those whose gender identity and birth sex are discordant. One study of university students found that roughly twice as many transgender persons were identified using a two-step method as compared to a one-step method, in which a single question was used querying sex/gender and allowing responses of *male, female*, and *transgender* (Tate, Ledbetter, & Youssef, 2013). Although some have expressed concern that routine collection of gender identity information could place patients at risk of discrimination, researchers at the Fenway Institute have found that "patients seem as willing to provide [gender identity] information as financial information" (Cahill & Makadon, 2014, p. 37). Some agencies such as the Health Resources and Services Administration (2010) have not yet adopted the two-step method and therefore may report statistics that do not accurately represent the impact of HIV in the transgender community. Given that transgender women in the United States have been shown to have an HIV seroprevalence of 21.7% (odds ratio 34.2), insuring widespread accurate and consistent recording of gender identity data is essential to inform the development and support of HIV-related services specific to the transgender community (Baral et al., 2013).

Little evidence exists to guide the actual mechanics of gender identity data collection. Such information may be collected in various ways: in face-to-face questioning by clinic staff or providers, via a pen-and-paper form to be entered into the EMR, or by self-report via electronic kiosk or online patient portal. Research has suggested that self-reporting via an electronic system may yield more accurate information. Participants in a mixed-methods study of young adults presenting to community clinics reported being more honest and feeling less judged when using a tablet-based touch-screen interface to report sexual histories than with a face-to-face interview by a provider; such a method was also reported to be simpler to use and "fun" (Mackenzie et al., 2007).

Our study had two primary aims: (a) to determine current clinician end-user practices for the documentation of gender identity-related information within EMRs (preferred name, preferred pronoun, birth-assigned sex, and gender identity); and (b) to determine the mechanics with which such information is collected from patients. Quantifying current clinician practices will provide an assessment of need for guidance in this area; inform efforts to further develop, test, standardize, implement, and disseminate best practices such as the two-step method and the WPATH EMR Working Group Recommendations (Deutsch et al., 2013); as well as illuminate areas for future study such as actual collection mechanics.

Materials and Methods

Study design and methods were reviewed and approved by the Committee on Human Research at the University of California – San Francisco. A survey was electronically distributed in May 2013 to a convenience sample of subscribers to the WPATH

listserv as well as in person at the May 2013 National Transgender Health Summit in Oakland, California. Inclusion criteria were self-identification as a health care provider, in a U.S.-based practice, and a user of EMRs in the care of transgender patients. Study data were collected and managed using REDCap electronic data capture tools hosted at the University of California – San Francisco (Harris et al., 2009). Data were downloaded and analyzed using Microsoft Excel (Microsoft Corporation, Redmond, WA) and Stata IC-12 (StataCorp LP, College Station, TX).

Results

The respondent sample ($N = 67$) represented a diverse range of educational degrees, practice settings, and specialties. Fifty percent of all respondents practiced in a primary care setting and 31% were in a mental health setting. Other disciplines included endocrinology, obstetrics/gynecology, plastic and general surgery, and pediatrics. Physicians (MD/DO) comprised 49% of respondents, doctoral-level psychotherapists 13%, and nurse practitioners and masters-level psychotherapists were represented at 9% each. Other degrees represented included social workers (8%) and physician assistants and pharmacists (both 3%). Practice type was diverse, with nonprofit represented at 51%, private practice at 18%, academic at 24%, and public at 5%.

While only 51% reported implementation of a practice management module, 85% reported an EMR (chart notes) module; only 27% reported decision-support implementation. Nearly 50% of respondents reported using systems made by one of three vendors, while an additional 10% reported using a locally developed/in-house system. Slightly more than half of respondents reported having a single field for collection of both sexual orientation and gender identity rather than separate fields for gender identity and sexual orientation. Some 27% reported an ability to record preferred pronoun, and 55% reported an ability to record preferred name.

Locations within the EMR chart where these data were stored, as well as the methods by which they were collected from the patient, were heterogeneous (Figures 1–3). Gender identity and birth sex were most commonly stored in the demographics field. Preferred name was most commonly stored in a preferred name or nickname field. Storage of preferred pronoun was much more heterogeneous, with a relatively even split between a dedicated preferred pronoun field, other demographics field, or within an alert or reminder system, the social history, or another unlisted location. Preferred name was visible to all users in all views in 47% of responses, and preferred pronoun was visible to all users in all views in 27% of responses. Proportion of reported use of electronic kiosks and patient portals for data collection were low.

Discussion

Our study represented the first attempt to quantify current clinician practices in the documentation of gender identity information within EMRs. Findings in general were heterogeneous and suggested a lack of standardization in gender identity data collection practices. Totals for the preferred name, preferred pronoun, gender identity, and birth sex questions, as well as the collection mechanics question, exceeded 100%, indicating respondent ambiguity, lack of consistency within the EMR itself, or some combination of the two. Regardless of the root cause, this finding indicated a great need for provider education and system standardization. Efforts will need to be focused on vendors, who will require support and guidance in implementing such recommendations. That 10% of respondents used a home-grown system demonstrated that there will be a need for support and technical assistance resources with adequate granularity for single-site implementations. Providers and site information technology directors will require education and guidance on correct use and collection methods.

While preliminary data suggest transgender persons are comfortable providing gender identity information, it is not clear how broadly applicable these findings are. Furthermore, differing levels of information access may be appropriate depending on which stage the patient is at in gender transition. For example, consider a patient who is now post-transition and fully settled into a new role (with all legal documentation updated to reflect preferred name and gender information). An ideal EMR implementation would provide a clear means of documenting and

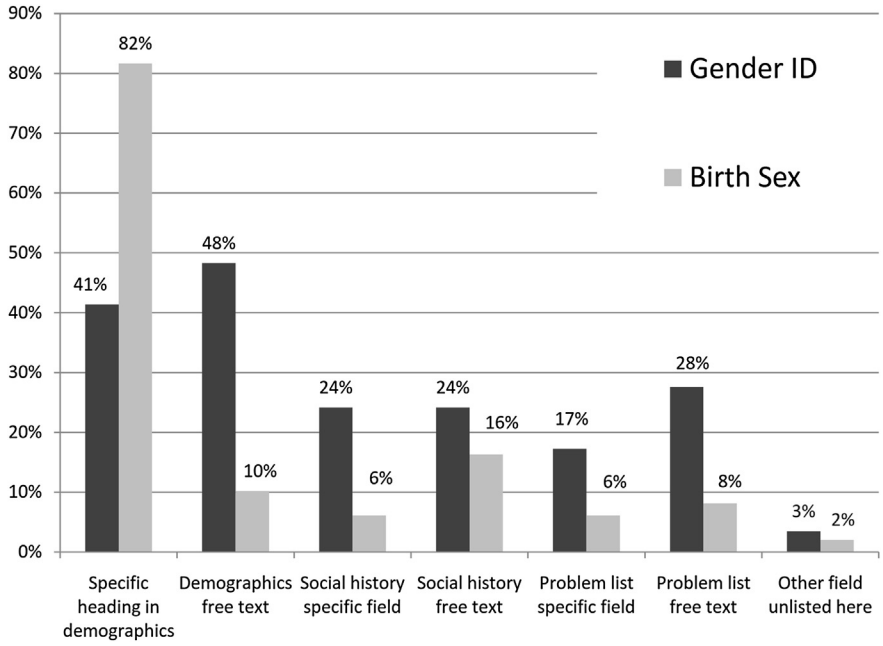

Figure 1. Location within electronic medical record (EMR) where gender identity and birth sex are stored. Percentage denominators sourced from total number of respondents who indicated they collect these data in some capacity. Gender identity $n = 29$; birth sex $n = 49$.

alerting medical providers to the details of the patient's history through a problem list or some other mechanism (i.e., any surgical history, current organ status); however, it would not be necessary (and may not be appropriate) for an EMR to broadly disclose transgender status to registration clerks, phlebotomists, or other staff in health care systems.

The mechanics of data collection also deserve attention and further study. Our participants reported relatively low utilization of self-report (rather than interviewer-driven) methods. Patients are likely to be more comfortable and truthful reporting gender identity data through self-report techniques; in the era of patient portals and low-cost tablet computers, such processes not only seem feasible but also would improve data quality and reduce clinic workloads. Such self-reporting modes could be designed to include feedback systems that provide guidance on a range of topics from HIV prevention to preventive health screening to alerting providers about anatomical differences prior to entering the room, and removing the awkward burden on the patient to report these considerations while in a potentially vulnerable position.

Our study had several limitations. The sample size of 67, with smaller numbers responding to certain questions based on skip patterns, limited the significance of the findings. A convenience sample was used. This may have limited the generalizability of the findings. We did not attempt to determine the institution of the respondents, and it was possible that more than one respondent from a given institution participated in the survey. This may have biased the observed study results. Given that the sample was recruited from within a community of providers who already had some fluency or at least interest in transgender health, these results may have represented a more optimistic picture than actually exists on a broader scale. However, the findings were so heterogeneous that they could arguably stand on their own in demonstrating an area in great need of standardization.

It would seem intuitive that study of current vendor practices and implementation of available products is also warranted. Such an investigation, however, would be limited by the potential for response bias on the part of vendors, as well as the reality that many end-user implementations represent

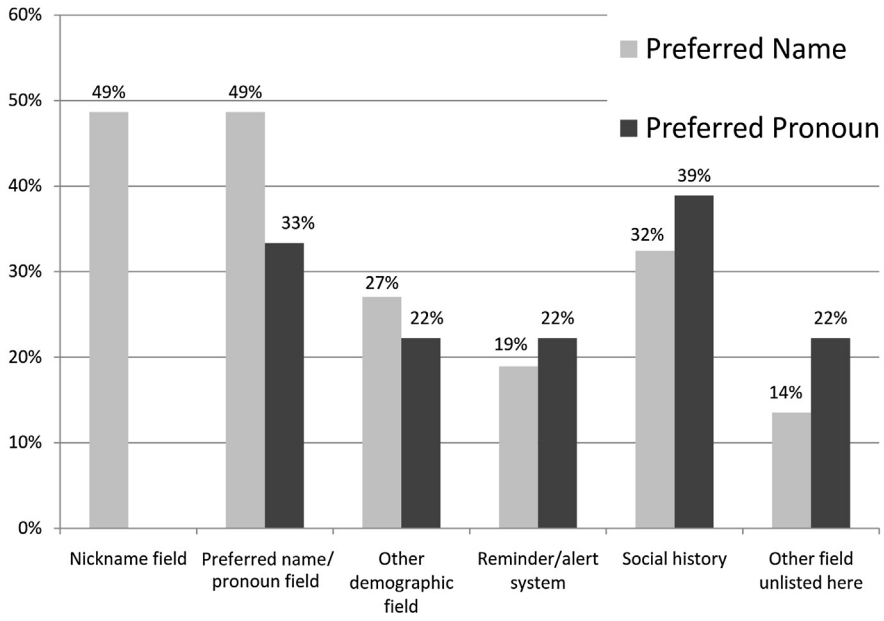

Figure 2. Location within electronic medical record (EMR) where preferred name and pronoun are stored. Percentage denominators sourced from total number of respondents who indicated they collect these data in some capacity. Preferred name $n = 37$; preferred pronoun $n = 18$.

local adaptations and customizations of more generic vendor products. Furthermore, frequent version upgrades and updates result in myriad implementations and practices, as demonstrated by the widely varying results presented here. Informal discussions with several vendor representatives during the development phase of this study reinforced these concerns and, as such, the decision was made to focus the

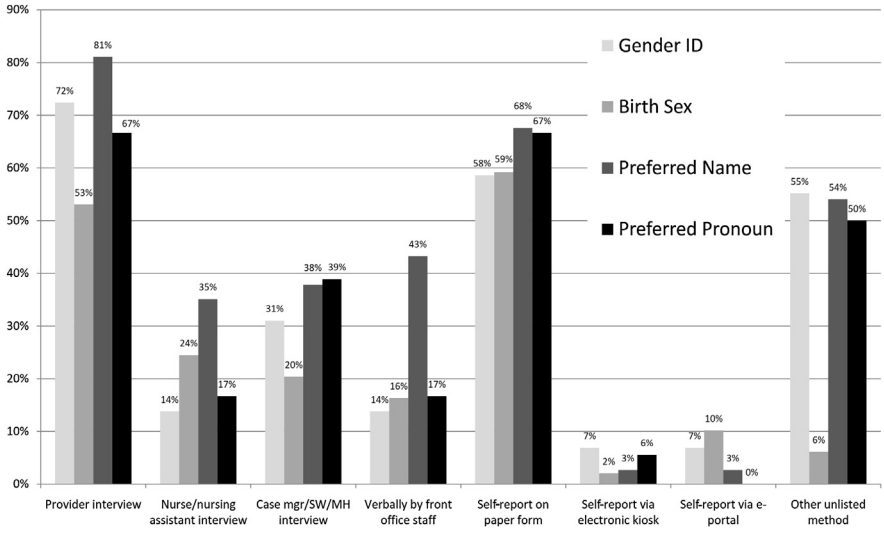

Figure 3. Method by which gender identity information is collected. Percentage denominators sourced from total number of respondents who indicated they collect such data in some capacity. *Note*: SW = social work; MH = mental health.

project on end-user experiences. Barring incorporation of gender identity data into meaningful use guidelines, it is nonetheless hoped that the disparate findings from our study will motivate both vendors and local implementation teams to devote resources to address this important issue.

Conclusions

Accurate and appropriate collection and documentation of gender identity information within EMRs is essential for improving transgender health at the individual and community levels. Appropriate and consistent collection of gender identity data would have a positive impact on three important domains: epidemiology (facilitating policy, research, and quality improvement efforts); medical (improving usefulness of health record data to providers and decision support systems); and patient-centered practice (improving patient experiences through the use of preferred names and pronouns). Capacity for the collection and use of a range of gender identity-related information is limited in the current landscape of EMR implementations; what capacity and processes do exist are heterogeneous in nature and lack standardization. More research is needed on a range of topics to inform best practices for what data to collect, how to collect these, and where within the EMR such data should be stored. In addition to vendors and system administrators, clinicians (especially those with limited experience with and exposure to transgender patients) will likely require education in these practices; inclusion in Meaningful Use guidelines is an essential next step. Developers and implementation teams should consult currently available evidence and recommendations to guide their practices. Given the limited and preliminary nature of current literature on the subject, system developers as well as implementation teams should use a rational approach mindful of the importance of accurate and consistent gender identity data collection.

Disclosures

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

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